

### A voice of our own

### **NDIS Review**

### **Cost and Affordability**

Submission 2 to the NDIS Review responding to *The role* of pricing and payment approaches in improving participant outcomes and scheme sustainability Paper

AUG 2023

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*NDIS Review Cost and Affordability – Submission 2 to the NDIS Review responding to* The role of pricing and payment approaches in improving participant outcomes and scheme sustainability *Paper* 

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### About PWDA

People with Disability Australia (PWDA) is a national disability rights and advocacy organisation made up of, and led by, people with disability.

We have a vision of a socially just, accessible and inclusive community in which the contribution, potential and diversity of people with disability are not only recognised and respected but also celebrated.

PWDA was established in 1981, during the International Year of Disabled Persons.

We are a peak, non-profit, non-government organisation that represents the interests of people with all kinds of disability.

We also represent people with disability at the United Nations, particularly in relation to the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

Our work is grounded in a human rights framework that recognises the CRPD and related mechanisms as fundamental tools for advancing the rights of people with disability.

PWDA is a member of Disabled People's Organisations Australia (DPO Australia), along with the First People's Disability Network, National Ethnic Disability Alliance and Women with Disabilities Australia.

DPOs collectively form a disability rights movement that places people with disability at the centre of decision-making in all aspects of our lives.

'Nothing About Us, Without Us' is the motto of Disabled Peoples' International.



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### Introduction

The Minister for the National Disability Insurance Scheme (NDIS), The Hon Bill Shorten MP, announced an independent review of the NDIS (the Review) on 18 October 2022. The review examines the design, operations and sustainability of the NDIS, and NDIS workforce capability and capacity.

People with Disability Australia (PWDA) welcomes the Review and welcomes this opportunity to comment.

This submission is a response to NDIS Review paper released in May 2023: <u>The role of</u> <u>pricing and payment approaches in improving participant outcomes and scheme</u> <u>sustainability</u>. It will respond to each of the findings:<sup>1</sup>

- **Finding 1**: There are opportunities to improve NDIS pricing arrangements over the short- to medium-term.
- Finding 2: The fee-for-service payment approach rewards NDIS providers for the volume of supports they deliver, rather than for supporting participants to achieve outcomes.
- **Finding 3**: A lack of transparency around prices, volume, quality and outcomes is restricting the effectiveness of NDIS service delivery.
- **Finding 4**: Removing price caps could place pressure on scheme costs. Instead, the focus should be on foundational market reforms that help align incentives for participants, providers, and governments.

In responding to the paper, this submission will address the following Terms of Reference of the NDIS Review:

<sup>&</sup>lt;sup>1</sup> NDIS Review (2023). <u>The role of pricing and payment approaches in improving participant outcomes and scheme sustainability</u>, accessed 24 July 2023



#### Part 1 - Design, operations and sustainability of the NDIS

b) Fiscal sustainability of the Scheme

c) Delivery of values and outcomes to participants

g) financial risks and the drivers of cost pressures, and the most appropriate levers to manage these risks and cost pressures.

#### Part 2 - Building a more responsive and supportive market and workforce

a) Foster and steward an innovative, effective and sustainable market

b) Improve the pricing and payment system to incentivise providers to improve outcomes

h) improve the efficiency and effectiveness of current price setting and regulatory functions (market oversight, monitoring and enforcement), including interaction with other relevant Commonwealth, state and territory regulatory systems; and

i) improve performance monitoring, compliance, reporting and responses to breaches, unscrupulous behaviour, including the detection of fraud and sharp practices.

In addition to responding to the Terms of Refence, PWDA will address two key questions from the NDIS Review What Have We Heard report (June 2023) in this submission:

- 1. How can the markets be better designed, structured and supported?
- 2. What needs to be done to ensure the markets serve the interests of people with disability, rather than the other way round?



### What is informing our response?

The National Disability Insurance Scheme (NDIS) is a transformative scheme for the provision of supports and services for people with disability.

PWDA has extensively and consistently advocated for a scheme that is fully funded and resourced to provide benefits for people with disability.

This submission is based on extensive consultations with our national membership of people with disability. From March to May 2023, PWDA conducted several focus groups (including one dedicated focus group on experiences with NDIS Services) and two online surveys (including one Easy Read version) which received 441 valid responses.

The findings from these consultation methods, as well as feedback from PWDA's Individual Advocates across New South Wales (NSW) and Queensland, and our expertise as the cross-disability Disability Representative Organisation (DRO) and Disabled Peoples Organisation (DPO) funded by the Australian and NSW Governments to provide systemic advocacy, have provided invaluable direction and evidence for the development of this submission.

More information about the surveys and the focus group, including the background and demographics of the surveys and focus groups, can be found in the appendices of this submission.



### **Proposed NDIS market principles**

Based on the consultations that PWDA conducted with our national membership, this submission will demonstrate and conclude that foundational market reforms are needed.

While the current approach to the market, particularly the fee-for-service model, has been beneficial in enabling more choice for participants in the market, the current market approach has not provided for all.

Noting the forthcoming and potentially significant changes that will arise from this NDIS Review, as well as the Final Report of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, PWDA proposes that any and much needed market reform be based on the following NDIS market principles.

The below proposed NDIS market principles reflect what PWDA has overwhelmingly heard from our national membership and people to whom we provide individual advocacy support.

#### Principle 1 - The NDIS delivers measurable benefits for NDIS participants.

This must be recorded, be publicly available and used in public dialogue to discuss the benefits delivered to NDIS participants, to shift sole focus on scheme cost and sustainability in public discussion about the NDIS.

Principle 2 - The NDIS market needs to be able to provide equitable access to all participants regardless of their physical location.

Thin markets should not be a reason for not being able to access the same services or supports as participants in areas where they have traditionally had greater choice and access to services and supports.



Principle 3 - Any future proposed changes to the NDIS Act and delegated legislation to support better market stewardship and oversight must be codesigned with people with disability and their representative organisations.

This must include changes to NDIS Rules, and all co-design activity must include sufficient time and resources to engage in the co-design process.

Principle 4 - There should generally be no return to block funding in the NDIS market, unless the block funding is for a specific purpose that meets an agreed upon identified need, is time-limited, and is consulted on with DRCOs.

The identified need must further facilitate positive outcomes for people with disability. DRCOs must be consulted and party to the agreement of what constitutes an identified need.

Principle 5 - There should be a limited use of blended payments in the NDIS market, and if used it, must be time-limited and be for a specific purpose that meets an agreed upon identified need and co-designed with DRCOs.

Similarly, the identified need must further facilitate positive outcomes for people with disability and DRCOs must be consulted and party to the agreement of what constitutes an identified need.

Principle 6 - Any future changes to the NDIS must ensure the diverse, intersectional needs of all NDIS participants are met through service delivery and supports, especially the needs of people with disability who may also identify as First Peoples, LGBTIQA+ and/or culturally and linguistically diverse (CALD).

This could be meet through the provision of funding for provider capacity-building, especially community-controlled organisations, including First Peoples, people with disability from culturally and linguistically diverse backgrounds, and/or LGBTIQA+, who can provide services and supports for people with disability from diverse backgrounds.



# Principle 7 - Registered and unregistered providers must be allowed to continue to operate in the NDIS markets.

However further consultation is needed to ensure types of providers (e.g., housing providers) are mandatorily registered to promote visibility of, and enforcement of actions, with oversight by the NDIS Quality and Safeguards Commission.

Principle 8 - All information provided to NDIS participants, including the NDIS portal, must be accessible to all participants and meet communication needs.

Principle 9 - All NDIS service providers provide transparent information for all NDIS products, in accessible formats.

This information must include, but not be limited to information about:

- how it supports people with disability from diverse backgrounds e.g., First People, LGBTIQA+, and/or CALD
- pricing
- additional costs that might be incurred, and;
- quality information, including what safeguarding mechanisms and consumer protection/s are in place to protect NDIS participants.



### What people with disability told us

The feedback from PWDA's national membership of people with disability, obtained through multiple surveys, focus groups and consultations with our large network of Individual Advocates across NSW and Queensland, have told a clear story about what needs to change to ensure NDIS markets serve the interests of people with disability, and rather than the other way round.

This feedback will be explored in this of the submission, and will:

- highlight key experiences of people with disability in the NDIS market
- provide feedback on what people with disability think about the current fee-forservice approach, and other payment options like blended payments and block funding, and;
- highlight the lack of transparency and provision of information to participants, which has negatively impacted the ability of people with disability to make informed choices.

# The experiences of people with disability in the NDIS market

#### Participant experiences of cost and sustainability discussions

**Principle 1 –** The NDIS delivers measurable benefits for NDIS participants.

This must be recorded, be publicly available and used in public dialogue to discuss the benefits delivered to NDIS participants, to shift sole focus on scheme cost and sustainability in public discussion about the NDIS.

PWDA heard from survey respondents that the consuming focus on cost measures, and cost-cutting has been detrimental for their self-worth as a person with disability. It is perceived that providers earning money is more important than the value of providing quality support and care to people with disability.



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"Providers think anyone can be a support worker because of a workforce shortage. This is not the case. People who value the inherent value of people with disabilities should be workers. I understand it is a Job and people need to be paid but I am not just a 'cash cow'. The NDIS is not free money. It is valuable taxpayers' money given to me to enable me to be a healthier, happier contributing member of my community."

Survey respondents also expressed that the belief that through their economic contribution and taxes paid, they deserve access to the NDIS that is fully resourced and funded to meet their needs so they can participate as full citizens in Australian society.

"My needs must be met and whatever the cost, it has to be paid. I am not an item on a balance sheet, I am a person. Furthermore, I have paid taxes all my life and also worked as a volunteer since I was 15. I am still the sole carer for my disabled adult son."

Another issue with the adverse discussion around sustainability of the NDIS has been the damage to the trust towards the NDIA, and future hopes for the NDIS.

"Stop nit-picking about exactly what it's spend on - being disabled is really expensive for all disabled folk. See the NDIS as compensating for that. There's no need to justify every dollar spent because it will inevitably flow to disability costs."

"The constant talk of how costly the NDIS is also cause me a lot of distress and increases the sharing of ableist views in the public. My life is not a burden."

Survey respondents noted beliefs that cost-cutting is an objective of the NDIS, not the provision of best practice and high-quality service to NDIS participants.

"The LAC is unable to provide any certainty of future funding. The planner (NDIS delegate) is unseen and unaccountable and appears to have a focus on cutting costs rather than providing best outcomes for the participant."



## The current approach: Participant experience of price capping, the price guide, and exercising choice and control

**Principle 2 –** The NDIS market needs to be able to provide equitable access to all participants regardless of their physical location.

Thin markets should not be a reason for not being able to access the same services or supports as participants in areas where they have traditionally had greater choice and access to services and supports.

Both survey respondents and focus group participants have expressed concerns around the quantity and quality of service provision directly resulting from the price caps provided by the <u>NDIS Pricing Arrangements and Price Limits</u> (previously known as the Price Guide) in the current market.

A consequence of market price capping is overcharging for service provision, thus limiting choice and control for some participants. Overcharging means there is less funding available for the supports a person with disability requires. For example, 20 hours at \$88 per hour is funded however the participant is charged at 20 hours at \$120 per hour, therefore the funding allocated by the NDIS will not cover all the hours of required service at the higher rate charged.

"The main problem is underfunding/not inclusion of required supports in the plan. The second reason NDIS sets prices in their price guide which becomes the new minimal price instead of market price. Providers charge too much. If you don't have funding they just stop providing services."

Alternatively, the NDIS market has enabled the entry of new service providers into the market, including sole traders who set pricing at a level to compete with larger providers, often undercutting the prices set by larger providers.

This has enabled greater choice and control to participants to set and choose the supports that align with their goals and values, while accessing the quantity of support that benefits them. Survey respondents have said this is the best aspect of the Scheme.

"Choice to use the private sector and not [be] reliant on disability-only services."



#### "Choice of support, options available with self-managing, self-autonomy."

Although price capping has had some of the intended benefit of the reason it was introduced, to enable greater choice and control in balance with quality of service, the quality of service has been compromised through Service Agreement clauses like the 7-day cancellation policy applied since 2022, that are being applied without considering whether the policy adheres to Australian Consumer Law.

"NDIS participants don't have choice and control - but the service providers all do. If you need/want support at certain time and staff are not available then you have no choice. Sometimes the options you have are not suitable. Cancellation policy times can be unrealistic. I can request support and then, if through no fault of my own, I have to cancel I can sometimes be charged for more hours than were requested."

Survey respondents also reported the shift in pricing upon disclosure of being a NDIS participant to a service provider or support supplier:

"[There needs to be a] closer watch on support services. So many sharks willing to overcharge; companies like [service provider] who do nothing about safety reports and how the price of everything doubles when you say NDIS. Wheelchair batteries were \$900 but when I mentioned NDIS it was \$1.600!"

Another issue is that the amount of NDIS funding is inadequate for the level of service provision needed to meet a participant's disability support needs. Focus group participants shared various examples of this occurring, with the consequence being that participants either had to forego part or all their supports or service.

"Sometimes the funding matched quote sometimes it hasn't matched the quote. I was grateful to have it match for my guide dog funding that was fantastic but there have been other times where I've got a quote and NDIS has only funded part of what I need so I basically had to go without support service because I didn't have the funds to pay for it."



Price capping was introduced to the NDIS market in the interests of encouraging "growth in supply while driving efficiency"<sup>2</sup> however the places where it has significantly and detrimentally impacted NDIS participant service has been in regional, rural, and remote areas, where thin markets have limited or completely eradicated service provision.

#### Service provision and product access in thin markets

In regional, rural, and remote markets, choice and control is naturally limited by a lack of choice of service providers. Participants in the regions are detrimentally impacted by incurring additional costs for service and support access including travel costs for the provider to travel to them or for the participant to travel to the closest area to access services.

"Supporting participants find help in country and regional areas where there is very little support due to thin markets. Understanding of transport costs to be able to access services or have people come to you, rather than just saying not our problem."

*"My distance from most supports and services either means they are unobtainable due to cost of travel, or pricing guidelines."* 

"Nobody wants to know about the barriers I face in accessing supports, such as travel cost to access supports which is unaffordable. I have to drive 50km to the nearest regional city to access support. I can't afford it. Nobody cares about helping me find affordable housing closer to supports."

"I have 2 providers where I live or providers have to come from 45kms away and all want to charge travel from 45kms away. The 2 providers we have, one has limited staff availability and the other wants to have workers work in their hub when I don't want to go to the 'hub' and spend my time grouped with others with disabilities."

<sup>&</sup>lt;sup>2</sup> NDIS Review (2023). <u>The role of pricing and payment approaches in improving participant outcomes and scheme sustainability</u>, accessed 24 July 2023, p.23



The impact on pricing in these areas is stark for NDIS participants who are unable or do not wish to self-manage their funding – only 30% of all current NDIS participants partly or fully self-manage their funding.<sup>3</sup>

"I live in a regional area where access to support workers, OTs physios etc is limited to non-existent. Two services I could engage locally are assistance with cleaning and lawnmowing, but the current rate these providers are charging is \$75+ per hour, which is 150% of the current price limit. I have more than enough funding to pay these rates but as I am plan managed, am not able to. I'm currently in the process of switching to selfmanaged so I can access these supports."

It may also mean that NDIS participants in areas where there are thin markets are having to compromise on the quality of service, or the service not fully meeting their needs.

#### **Conclusive insights**

The NDIS that the disability community advocated for in the years prior to the establishment of the NDIS was not one founded on a central ideology of fiscal sustainability, but one of quality care and support for people with disability.

Firstly, the rhetoric around sustainability needs to be shifted to align with the vision of the Scheme to provide high quality, safe and responsive support, and service to people with disability in a way that maximises choice and control.

Secondly, the NDIS market needs to be altered to create a NDIS where all NDIS participants, regardless of location have equitable access to services and supports. The current price capping measures introduced with the Pricing Arrangements and Price Limits has created a market environment which is not conducive to high quality service and support for all NDIS participants.

The market has not been responsive to participants' needs, particularly in thin markets created in geographical areas that are rural, regional or remote. In these markets, it is apparent that mechanisms implemented need to be different to respond to the needs of



participants e.g., accommodating the costs of provider transport to the participant or vice versa.

"There should be a workaround for clients in rural areas to access services that are only available from distant metro areas and the distance for the provider or the client to travel makes the cost prohibitive. For example, less strict pricing guidelines for services and less strict criteria for transport and travel allowance."

#### Fee-for-service payments and other payment options

**Principle 3 –** Any future proposed changes to the NDIS Act and delegated legislation to support better market stewardship and oversight must be co-designed with people with disability and their representative organisations.

This must include changes to NDIS Rules, and all co-design activity must include sufficient time and resources to engage in the co-design process.

#### The fee-for-service approach

Fee-for-service is an approach currently used by many service providers to organise pricing by support hours. The pitfall of the approach is that service delivery is increased by volume rather than by quality to enable financial reward for the provider.

Some NDIS participants who are self-managed are now exercising choice and control to use sole traders and smaller providers over larger providers. A focus group participant shared:

"Because I found in my experience, I've had a lot more positive experience with sole traders through [service provider] and they seem to be more personally invested and accountable without the red tape, they provide the service and nothing is lost in translation there and they're generally cheaper as well which is something that I look at as well, are the rates reasonable. Does the service provider have good reviews and similar values to me?"



Further, the fee-for-service approach does not mitigate the need for specialised support or even support that meets the needs and goals of the NDIS participant. Survey respondents shared:

"Living with complex disabilities is time consuming and well...complex, labour intensive and needs highly experienced support. I don't have the funding for these needs to be met. My life has been put at risk on multiple occasions and my quality of life is very poor. I can't even get someone to take me for a walk outside in the fresh air."

"The financial waste in the system makes me despair. I am unable to continue accessing pre-made meals from a meal delivery service, because the NDIS changed their rules about this. But they will find a support worker to cook for me, which is far, far more expensive (they were paying someone \$800 per week to cook meals for me! But a meal delivery service would be \$100-\$150)."

There have been several alternative payment approaches which have been raised however there are significant risks in pursuing these approaches. The following section will explore these risks, and discuss the care application for block funding and blended payments.

#### Alternative payment approaches

#### Issues with block funding

**Principle 4 –** There should generally be no return to block funding in the NDIS market, unless the block funding is for a specific purpose that meets an agreed upon identified need, is time-limited, and is consulted on with DRCOs.

The identified need must further facilitate positive outcomes for people with disability. DRCOs must be consulted and party to the agreement of what constitutes an identified need.

The primary model adopted for disability service prior to the introduction of NDIS was block funding, whereby governments directly funded service providers to deliver services.



Unfortunately, this model encouraged one-size-fits all service delivery instead of individualised approaches.

PWDA strongly discourage any venture towards the wholesale reintroduction of block funding across the entire market; it will move the NDIS away from the aim of supporting people with disability through meeting their individual support needs to achieve the lives that they want to lead.

However, PWDA recognises that block funding may be needed under limited circumstances. We would cautiously support block funding approaches if a specified need that furthers positive outcomes for people with disability is identified, and that identified need is agreed to through robust consultations with DRCOs. In these agreed upon circumstances, the application of block funding must be time limited.

#### Issues with blended payments

**Principle 5** - There should be a limited use of blended payments in the NDIS market, and if used it, must be time-limited and be for a specific purpose that meets an agreed upon identified need and co-designed with DRCOs.

Similarly, the identified need must further facilitate positive outcomes for people with disability and DRCOs must be consulted and party to the agreement of what constitutes an identified need.

A blended payment approach would take the aim of supporting NDIS participants to achieve their goals through impacting service performance and quality of delivery. A recent University of New South Wales paper entitled *Blended Payments: Lessons for the National Disability Insurance Scheme*<sup>4</sup> stated that:

"The substantial evidence base... does not find that blended payments necessarily deliver improvements in cost containment, improved quality or innovation in service delivery. What this literature tells us is that blended payments mechanisms can be complex and tricky to set up and without

<sup>&</sup>lt;sup>4</sup> The University of New South Wales Canberra (2022). <u>Blended Payments: Lessons for the National Disability Insurance Scheme</u>, accessed 24 July 2023



### careful consideration these can lead to a series of unintended or perverse consequences for providers and service users."

It is PWDA's position that a blended payment approach carries substantive risk of creating perverse incentives for providers. For example, causing "creaming behaviour", which is a term describing when services focus on a set of participants over service provision to the broader market, or "parking behaviour", which refers to:

### *"creating artificial situations that can maximise payments, without actually achieving the outcome."*<sup>5</sup>

Notwithstanding the perverse and/or unintended consequences of using blended payment, as discussed above, PWDA notes that there may be limited circumstances in which a blended payment approach is warranted to improve service delivery and outcomes for people with disability.

Similar to our concerns with block funding approaches above, blended payments should only be used in limited circumstances. If mechanisms can be set up to ensure a blended payment approach improves positive outcomes for people with disability and meets an identified need not met by another system/s, then blended payments could potentially drive innovation and improve service provision.

However, taking a blended payments approach must be considered carefully. Therefore, PWDA strongly recommends a co-design approach to be taken (as the Australian Government has done so with its <u>current trial</u> for blended payments) when considering under what circumstances a blended payment approach could be warranted.



#### Other market considerations

#### NDIS market diversification to meet diverse needs

**Principle 6** – Any future changes to the NDIS must ensure the diverse, intersectional needs of all NDIS participants are met through service delivery and supports, especially the needs of people with disability who may also identify as First Peoples, LGBTIQA+ and/or culturally and linguistically diverse (CALD).

This could be meet through the provision of funding for provider capacity-building, especially community-controlled organisations, including First Peoples, people with disability from culturally and linguistically diverse backgrounds, and/or LGBTIQA+, who can provide services and supports for people with disability from diverse backgrounds.

There are currently multiple gaps in the NDIS market that fail to meet the disability support needs of people with disability who identify as First Peoples, LGBTIQA+ and/or culturally and linguistically diverse (CALD).

The current NDIS market has not diversified enough to provide safe and targeted support to meet the needs of people in the above cohorts. This means that the NDIS services available to them may not be culturally safe, trustworthy, accessible, and inclusive for them.

#### I am a LGBTQIA POC [person of colour ... the quality of care is quite low for people like me... people from intersectional backgrounds"

"lack of training extends to the disability sector as a whole: when I attempted to use services, I've had to deal with microaggressions"

New market approaches are urgently needed to support the diversification of service delivery so that diverse and intersectional NDIS participants have their disability support needs fully met.

This may require upskilling existing community-controlled organisation, or other organisations which meet the needs of people with disability who identify as First Peoples, LGBTIQA+ and/or CALD, to build their capacity to provide disability supports.



This may also means providing funding and support to these organisations to provide services, over and above any additional and higher levels of funding that other service providers may receive in the future.

#### Registered and unregistered providers

**Principle 7 –** Registered and unregistered providers must be allowed to continue to operate in the NDIS markets.

However further consultation is needed to ensure types of providers (e.g., housing providers) are mandatorily registered to promote visibility of, and enforcement of actions, with oversight by the NDIS Quality and Safeguards Commission.

The question of which providers should be registered requires further discussion. The NDIS market currently operates with a mix of registered and unregistered providers. PWDA supports this approach continuing, however registration should be mandated for some providers, such as those who provide housing services.

However, a broader disability community conversation on which providers should be mandatorily registered needs to take place and the NDIS Quality and Safeguards Commission is the appropriate agency to lead this conversation.

There is a strong argument for any approach to the NDIS market to prioritise consumer protection for NDIS participants.

The evidence for consumer protection is clear. In 2021, an open letter issued jointly by the Australian Competition and Consumer Commission (ACCC), the NDIA and the NDIS Quality and Safeguards Commission acknowledged that:

"there are a number of emerging consumer issues within the disability sector, with some NDIS providers not meeting their consumer protection obligations."

There must be clearly articulated expectations on providers to ensure NDIS participants are not going to be unfairly disadvantaged in terms of using their NDIS funding when accessing their NDIS services. This may require amendments in the NDIS Act and delegated legislation to make this a mandated obligation for providers.



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If this occurs, people with disability and their representative organisations must be consulted with, prior to changes being implemented.

#### **Conclusive insights**

Under Finding 4 of the NDIS Review consultation paper: *The role of pricing and payment approaches in improving participant outcomes and scheme sustainability*<sup>6</sup> it is stated that:

"Over time, replacing price caps with more 'light touch' pricing arrangements as currently intended... could encourage greater competition."

It is suggested that instead of this approach:

### "a market-based approach for the NDIS should instead focus on foundational market reforms."

PWDA strongly supports this position for foundational market reforms instead of any 'light touch' approach.

We are concerned that any move to price deregulation could detrimentally impact NDIS participants' access to services, with escalating costs making access more restricted for participants. If prices are increased, the NDIA should immediately review and revise plans to accommodate any new costs that market reform brings forth.

Further, benchmarking all services against each other is impractical if not impossible; it is far easier to benchmark mainstream disability services e.g., services that provide supports like cleaning, cooking that are general in nature against each other, then against services that provide specialist support, e.g., services that provide specialist support like enteral nutrition (tube feeding).

The current NDIS market is not working to ensure the best outcomes for NDIS participants. A fee-for-service model is not achieving the desired outcomes for participants, however other approaches block funding or blended payments are not ideal either.

<sup>&</sup>lt;sup>6</sup> NDIS Review (2023). <u>The role of pricing and payment approaches in improving participant outcomes and scheme sustainability</u>, accessed 24 July 2023, p.5.



Market reform is needed.

Therefore, we suggest an alternative approach to market reform that involves codesign, and this approach would explore how NDIS participants can access services and products with confidence that they are not being overcharged or are not getting quality in service. PWDA supports a principle for codesign and consultation with people with disability and Disability Representative Organisations (DROs) prior to any market reforms being implemented, and in the future, reviewed.



# Lack of transparency and provision of information to participants

The barriers to the implementation of pricing arrangements and limits are two-fold:

- a lack of transparency around pricing arrangements, and;
- the inaccessibility of information available for participants.

#### Inaccessibility of the NDIS Portal

**Principle 8 –** All information provided to NDIS participants, including the NDIS portal, must be accessible to all participants and meet communication needs.

For survey respondents and focus group participants managing their own funding, the inaccessibility of the NDIS portal was reported. This was both in terms of accessibility for screen readers, and more generally, for use.

"The accessibility issues with the portal need to be addressed, as I had no way of knowing why it wasn't working whenever I tried clicking that Next button using keyboard navigation."

"I do not know how to access the portal, to check how much funding I have when - NDIA managed they send me the service agreement and I sign it but I don't know how to check the portal so I don't know how to check whether my quotes are fair or not."

"We then did a decision review which approved the funding and also gave me permission to self-manage the major home mods. Problem was they hadn't told the computer system, so I couldn't access the funds via the portal as someone who was self-managing. It took another 6-8 weeks for them to work out how to give me portal access to those funds."



# Transparency of pricing and access to information about services including costs

**Principle 9 –** All NDIS service providers provide transparent information for all NDIS products, in accessible formats.

This information must include, but not be limited to information about:

- how it supports people with disability from diverse backgrounds e.g., First People, LGBTIQA+, and/or CALD
- pricing
- additional costs that might be incurred, and;
- quality information, including what safeguarding mechanisms and consumer protection/s are in place to protect NDIS participants.

Focus group participants shared the challenges in reviewing service providers prior to access, both in terms of pricing and quality of service.

Participants need publicly available information about service providers and/or sole traders, including what is disclosed by the provider on their website, Google reviews, social media reviews, and word of mouth information from peers with disability. PWDA has heard that participants are generally inclined to trust peer opinion more than other sources.

"I'll look at a service providers website, maybe check reviews, any service provider is probably going to put only positive stuff on their website from clients and carers. Facebook ... particularly one group."

"Does the service provider have good reviews and similar values to me so I go and have a look... people can rate support workers on [Service Provider] so I have a look at their ratings and feedback from other clients."

In terms of comparing services on cost, providers may use the upper limits of what is listed in the NDIS Pricing Arrangements and Price Limits Guide (formerly Price Guide). However, providers may also not adhere correctly to the Guide at all. It is left to the participant to determine if the Guide is being correctly used by the provider. Survey respondents reflected this experience.



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"The main problem is underfunding/not inclusion of required supports in the plan. The second reason NDIS sets prices in their price guide which becomes the new minimal price instead of market price. Providers charge too much. If you don't have funding they just stop providing services."

"Yes so some providers are charging incorrectly (not aware or experienced in price guide), others are not providing me the quality I need (I only find this out when I change provider) and I also don't have the funds to support it."

There are also costs that are not considered in the allocation of funding, for example, trialling equipment prior to using provided funding to purchase the equipment which has been approved by the Scheme.

"AT was added incorrectly to my plan. Funds were not added to facilitate rental or trials of the new equipment I required, except via quote required line items. This necessitates a much longer process for each trial."

Further, there is often additional charges added to service cost for perceived auxiliary support e.g., sending emails or making phone calls related to the NDIS participant and/or service.

*"Providers charge ridiculous amounts for things. For example, charging to send an email or take a phone call."* 

Survey respondents also shared that price setting changes depended on whether the person accessing the service is a known NDIS participant to the provider.

"Costs go up as soon as an organisation gets a whiff of possible NDIS funding. There is as attitude of, "why do you care, it isn't your money?"

In addition, the lack of clear information makes it challenging for participants to articulate needs in planning meetings, even if those needs are already explored in supporting documentation provided to the person conducting the planning meeting. This leads to services being cut from participant's plans.

*"[During my planning meeting], I was then asked subsequent questions which are outside of my area (i.e., asking what is the difference between* 

providers and why are both requested?). Following receipt of my plan, I experienced cutbacks on supports indicating there was double up of services - yet it was never explored about what each provider was bringing to my plan (although the reports detailed this)... I've decided not to appeal as I need a break. It's causing flare up in my symptoms worrying about NDIS. I'd rather focus on being grateful and accept what has been given to date."

There are currently no single sources of information to compare services across cost, quality of service or the ability of services to meet intersectional needs.

#### **Conclusive insights**

NDIS participants can currently only make decisions around service provision based on the information that is available to them about the service, and in each case, the amount of information they can access about pricing and quality of service vastly differs. Participants use a variety of sources to determine if they wish to use a service, with peer reviews being the highest trusted source.

There needs to be a better ability for NDIS participants to make informed choices when selecting services based on price and service quality. Participants need access to information in accessible formats that they can trust and compare directly across providers to choose their services and supports with confidence.



### Conclusion

The participant experience of the NDIS has a strong relationship with the operation of a NDIS market that meets the needs of all people with disability.

Based on the feedback PWDA gained from the consultation methods we employed to develop this submission, it has become clear that foundational market reforms are needed. Unfortunately, over the course of the 10+ years that the NDIS has operated, the market has evolved in a way that has created barriers to delivering best practice supports and services to people with disability.

While the current approach to the market, particularly the fee-for-service model, has been beneficial in enabling more choice for participants in the market, it has not mitigated the need for specialist services for complex needs, or services that meet the needs of diverse and intersectional people with disability. The current approach has also not mitigated issues of overcharging for service provision.

Additionally, the recent and ongoing public dialogue centred around sustainability and cost burdens of the NDIS, have contributed to a culture of mistrust from people with disability towards the Scheme, and has had a demoralizing impact on people with disability.

Further, the market has failed in places where thin markets exist e.g., rural, regional, and remote areas, especially in the absence of a provider of last resort. In thin markets, the costs associated with travel and distance from service providers have also not been considered in pricing arrangements, leading to less service at higher costs.

Alternative models for the NDIS market, including block funding and blended payments will not alleviate the issues that have been created within the NDIS market.

PWDA strongly supports changes to the NDIS market that encourage diversification in service delivery and support to NDIS participants. This diversification needs to address the current service and supports shortage for people with disability with intersectional needs. Further, it must encourage wider reach into traditionally thin markets, through the upskilling of providers to deliver the needed supports in these communities.



Foundational market reforms could be addressed through amendments to the NDIS Act and delegated legislation. However, PWDA only supports changes that occur with the fulsome and robust consultation of people with disability and their representative organisations such as PWDA. This must include sufficient time and resources to properly engage with any proposed changes.

To ensure that NDIS participants also have confidence in the safety and quality of NDIS services, PWDA strongly supports transparent and accessible information provision to participants, to enable choice and control about the services and supports they access in the NDIS market.

Further, we support mandated registration for parts of the market e.g., housing providers, to ensure visibility and transparency of safe and quality operation. However, a broader disability community conversation on which providers should be mandatorily registered needs to take place with oversight by the NDIS Quality and Safeguards Commission.

Finally, we encourage funding provision for capacity-building for organisations, including community-controlled organisations, to improve the capacity of the market to meet the intersectional needs of NDIS participants. This way the targeted support needs of people with disability who identify as First Peoples, CALD and/or LGBTIQA+ are better met.



### Appendices

#### Appendix A - Background on Surveys and Focus Group

#### Surveys

PWDA conducted a NDIS Review survey through Survey Monkey which was open to all Australians with disability, both who were NDIS participants and who are not NDIS participants.

The survey PWDA conducted sought to better understand the impact of the NDIS across geographic areas and across different groups of people. In this report we refer to this survey as the non-easy read survey and responses to this survey are shown in the graphs below as non-easy read.

We asked for feedback about what are the current barriers in NDIS access and service support, what is working well, and where improvements could be made.

With the support of Inclusion Australia, PWDA also developed an Easy Read version of the survey for people with intellectual disability and other communication needs using RIX software. In this report we refer to this survey as the easy read survey.

Within the Easy Read survey, people were asked *Are you a person with disability*? If they answered yes, they are represented in the Graphs below as respondents to the easy survey. If the answer was *No but I am supporting a person with disability to fill out the survey*, they are represented in the Graphs below as respondents on behalf of.

A total of 441 valid responses were collected from the two surveys. Of these, 381 valid responses were collected from the non-easy read survey. There were 60 valid responses to the Easy Read survey, 41 were provided by people with disability and 19 were provided by people supporting a person with disability to fill in the survey.

Within each of the surveys, people were asked whether they were a NDIS participant. As shown below, people answered either yes (n=372), no (n=23) or no, but I would like to be (n=46).



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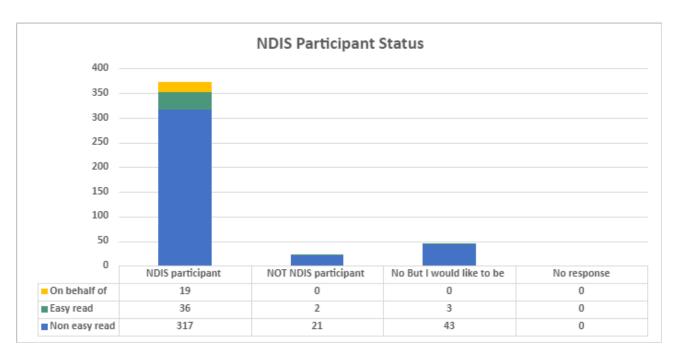


Figure 1. NDIS Participant Status of survey respondents

#### **Focus groups**

PWDA also conducted a series of focus groups on the NDIS, including a targeted focus group on Experiences with NDIS services.

The targeted focus group on experiences with NDIS services was held on 11th May 2023, running for 2 hours with 7 participants aged 43-65 who were all NDIS participants. The focus group was facilitated by an independent consultant who is a person with disability.



# Appendix B - Combined Easy Read and Non-Easy Read survey demographics

Age group demographics	Number of respondents
10 - 17 years	16
18-24 years	26
25 - 39 years	113
40 - 55 years	170
56+ years	111
Did not answer	5
Total	441

Gender identity demographics	Number of respondents
Female	277
Male	120
Non-binary	23
Genderfluid	4
Genderqueer	1
Agender	4
Prefer not to say	12
Did not answer	0
Total	441



First Nations demographics	Number of respondents
Identifies as First Nations	20
Does NOT identify as First Nations	402
Prefer not to say	19
Did not answer	0
Total	441

LGBTQIA+ demographics	Number of respondents
Identifies as LGBTQIA+	106
Does NOT identify as LGBTQIA+	312
Prefer not to say	23
Did not answer	0
Total	441

CALD demographics	Number of respondents
Identifies as CALD	65
Does NOT identify as CALD	360
Prefer not to say	16
Did not answer	0
Total	441

Area of respondent	Number of respondents
Metropolitan	306
Rural	115
Remote	2
Did not answer	18
Total	441



State demographics	Number of respondents
NSW & ACT	144
VIC	107
QLD	94
SA	22
WA	40
NT	1
TAS	16
Did not answer	17
Total	441

NDIS Participant demographics	Number of respondents
NDIS participant	372
NOT NDIS participant	23
NOT NDIS participant, would like to be	46
Did not answer	0
Total	441



My disability is best described as	Total
Physical	74
Acquired brain injury	5
Intellectual	39
Neurological	27
Psychosocial	16
Autism	30
Cerebral Palsy	25
Multiple Sclerosis	17
ADHD/ADD	3
Sensory – Hearing	2
Sensory – Vision	30
Multiple	138
Other	29
Not answered	6
Total	441



# Appendix C - Experiences with NDIS Services Focus group demographics

Age range of participants	Number of participants
18-24	1
25-44	3
45-65	3

Gender of participants	Number of participants
Female	7

States/territories	Number of participants
NSW	3
VIC	2
QLD	2

Geographic area	Number of participants
Metropolitan	4
Rural	3

2
2



Participant	How the participant self- identified their disability
1	Physical impairment
2	Psychosocial, neurological
3	Cerebral palsy
4	Cerebral palsy, chronic illness, psychosocial disabilities
5	Multiple sclerosis
6	Physical and psychosocial
7	Muscular skeletal/neuro



#### Appendix D - Experiences with NDIS Services focus group questions

**Question 1**: What do you consider when you're comparing and deciding on a service provider?

**Question 2**: Thinking about your services, and any quotes you have received for services, what happened when you received funding - did it match the quote and if not, what actions did you take?

**Question 3**: Have you ever had to query the cost charged for a service and if you did, what was the outcome?

**Question 4**: For supports that the NDIS hasn't funded, what other options have you sought to pay for the support/service?

Question 5: Considering your experiences, what solutions would you suggest?





People with Disability Australia (PWDA) is a national disability rights and advocacy organisation made up of, and led by, people with disability.

For individual advocacy support contact PWDA between 9 am and 5 pm (AEST/AEDT) Monday to Friday via phone (toll free) on **1800 843 929** or via email at <a href="mailto:pwd@pwd.org.au">pwd@pwd.org.au</a>

Submission contact Giancarlo de Vera Senior Manager of Policy E: giancarlod@pwd.org.au

